ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

NOVEMBER, 1991

"AIDS: My Teacher"

By Reverend David Presley

{Editor's Note: Reverend Presley most recently served as pastor of MCC of Wichita Falls, TX. He is currently in residence at Trinity MCC, Arlington, TX.}

"I'm sorry, Dave, it's AIDS." My doctor's words did not exactly come as a surprise. I had been HIV positive since the mid-80s and my mate had died of this crushing disease. However, a lack of surprise does not translate into a lack of horror at the news. I feared the productive phase of my life was over. How wrong I was! During the past 3-1/2 years (since my diagnosis with AIDS) I have continued to grow and develop as a person.

Life is a teacher. A person who lives with AIDS has the advantage of an additional tutor. I share here just some of the things I have learned from AIDS:

(1) Take one day at a time. I despise the song but have learned to cherish the philosophy. I have learned to focus my life on the joy and/or challenge that each day offers. I try not to get all-tied-up about what might happen tomorrow or next week and to zero in on the immediate day-at-hand (Matthew 6:34).

(2) Utilize resources available. It is appropriate to identify and to make use of the resources offered by our government and other interested and helpful parties. I have found that the assistance offered by public, private and religious organizations make the burden of living with AIDS much lighter. While financial aid has been important in an overwhelming sense, the emotional support that I have received has made the difference. Is this not what Christ intended? (Matthew 25:34-40)

(3) Maintain a sense of purpose. I have discovered that it is fundamental to "good" health for one to have a clear, strong purpose for living. Maintaining body functions is not enough. I am grateful for the places of service I have been able to fill these past few years in the Universal Fellowship of Metropolitan Community Churches. It is a challenge for our denominational leaders and our local churches to find appropriate areas of purposeful service for our HIV affected members. We can serve. Perhaps, even with an additional richness and depth, we can serve! (Hebrews 12:1-2)

(4) God is sufficient. During my years of ministry I have preached and taught about the sufficiency of God in all of our life's needs. This truth has become much more than an intellectual realization. It has truly become a spiritual reality to me. Even to the very "end" my relationship with Christ has not failed me. It has actually been an overcoming source of peace. (2 Corinthians 3:4-5)

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"Surviving The Holidays"

By Reverend Christine Oscar

{reprinted with permission from "Oil of Gladness" Vol. I, No. 5, Nov/Dec 1991}

Persons who are grieving often dread the holidays fearing that nothing will be the same since their friend, spouse or loved one has died and will not be there. The holidays are considered "high risk" times for persons in grief. Stong upsurges of grief frequently accompany the holidays, especially the first year or two.

The truth is, whenever a friend or loved one dies, we are not the same and everything, including the holidays will be different. One of the worst things we can do to ourselves or to one another is to pretend that "everything's okay" when it is not. That does not mean that we have to "cancel" the holidays but we may have to make some adjustments.

Here is a list of suggestions to help grievers during the holidays:

(1) Don't try to force the holiday spirit. The griever may alternately feel happy and then experience sudden sadness. Stay with your/their feelings and let them happen. Denial only causes our pain to fester.

Listen to your/their feelings. If feelings are allowed to surface, they are more likely to dissipate more quickly than if they are "stuffed."

(2) Decide ahead of time how you want to celebrate the holidays. Some people choose to keep "everything the same" and others want to "change everything." Each person should listen to their own grief and have permission to celebrate in the ways that best suit their needs at the time.

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"AIDS: My Teacher "(Cont'd from pg 1)

(5) Miracles are not just a first century phenomenon. They can be a part of our daily lives. Raised as a conservative Baptist, I was indoctrinated to believe that miracles were not a part of the contemporary Christian experience. I now know that the Love of God and the fervent prayers of God's people are a very integral part of the introduction of miracles into our lives. It is important to me to believe in a God who cares about my life and has the ability to do something about those areas that are filled with pain--both physical and emotional. (Hebrews 2:1-4)

Certainly this list could become endless. Let it be known that while an AIDS/HIV diagnosis is not a treasure in our lives, the lessons that it can teach can be precious to us. I would encourage others to remain open to learn and to grow as life offers its lessons. ▼

Whatever Happened to Ribavirin?

{repinted from Treatment Issues, Vol 5 #7}

For a long while the answer to this question was simply, "Not much." Studies repeatedly showed that ribavirin failed to inhibit HIV, except at levels that proved to be too toxic. Additionally, it was discovered a few years ago that in the test tube ribavirin was antagonistic to AZT. However, in an August 17 letter appearing in *Lancet*, a Belgian doctor noted that in the test tube ribavirin greatly enhances the anti-HIV activity of ddI without increasing toxicity of the infected cell. The PWA Health Group will attest to the quickness with which good news travels; ribavirin is back in demand, according to a representative of the New York City underground buyers' group. ▼

Hypericin Trial Begins in New York, Boston, Minneapolis

By John S. James

{reprinted with permission from AIDS Treatment News, #138, Nov 1, 1991}

The long-delayed phase I/II trial of synthetic hypericin has begun in New York; the fourth volunteer received the drug on October 28. The two other trial sites, in Boston and Minneapolis, are expected to begin soon. Volunteers are needed at the Boston, Minneapolis, and possible New York sites.

Hypericin is an antiviral which has been extensively covered in *AIDS Treatment News* for over three years (starting with issue #63, August 26, 1988). This potential drug is important because it has shown quite promising results in laboratory tests with HIV, including "wild" strains directly taken from patients; in the laboratory, it suppresses HIV infection in freshly-drawn human blood. And in animal tests, it has been found effective in treating diseases caused by other retroviruses (other than HIV, which is difficult to study in animals).

In addition, hypericin has long been in human use as low-dose herbal extracts of the St. John's wort plant; this experience, as well an animal tests with larger doses, suggest that it might be nontoxic in doses large enough to be useful. And if it does prove feasible as a treatment, hypericin might be especially valuable since its mechanism of action appears to be entirely different from that of AZT, ddI, ddC, or any other treatment available, meaning that the drug might provide a new kind of therapeutic option. Animal studies indicate that hypericin can be used orally (although the new trial will administer it intravenously in order to obtain the most precise data), and that it does cross the blood-brain barrier.

Hypericin might also be useful against certain other viruses, possibly including cytomegalovirus (CMV) and hepatitis B.

Previous trials of hypericin have only used the crude St. John's wort preparations which were available, but which contain much less than one percent of the active drug; the results of these trials have been modest at best, and laboratory studies suggest that the doses obtainable this way may be much too low to be effective against HIV. In the animal studies, best results have been obtained with pure hypericin chemically extracted from the plants. But chemically synthesized hypericin, not the plant extract, was chosen for development as a human drug.

Synthetic hypericin is being developed by VIMRx Pharmaceuticals Inc., located in Stamford, Connecticut. In September 1991 U.S. patents were issued to New York University and to Yeda Research and Development Company Ltd., which commercializes inventions from The Weizmann Institute of Science, which in turn has worked with New York University and VIMRx on antiviral uses of hypericin; previous European and U.S. patents had been issued to Yeda. The clinical trial is being supported by the AIDS Clinical Trials Group (ACTG) of the U.S. National Institute of Allergy and Infectious Diseases. The principal investigator is Fred Valentine, M.D., of New York University.

The Trial

The new trial is designed primarily as a safety study, but will also look for evidence of anti-HIV activity. It will test four escalating doses of hypericin, ranging from 0.25 mg per kg of body weight, to 2.0 mg per kg; all doses will be given intravenously, twice per week. Volunteers must have a T-helper count under 300, and five of the eight patients at each dose level must have positive p24 antigen (by the conventional tests).

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ALERT

ALERT is a monthly newsletter containing information on AIDS Legislation, Education, Research and Treatment. The Editor is Rev. Dr. Stephen Pieters. For information, please write: ALERT, c/o UFMCC, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029.

Hypericin Trial Begins...{Cont'd from pg 2}

Volunteers cannot use AZT, ddI, or any other retroviral during the trial, or within one month of starting; also, they cannot use any form of oral hypericin within one month of starting the trial. They cannot have an active opportunistic infection nor require continuous medication (other than pneumocystis prophylaxis) when they enter the trial. Short courses of most medicines are OK; but those which cause photosensitivity (increased sensitivity to sunlight) will not be allowed, because of the possibility that hypericin itself may cause photosensitivity.

For information about volunteering for this trial, contact the AIDS Clinical Trials Unit near you and ask for information about the hypericin trial (protocol #150). Note that the trial is being conducted only at the following three centers; and the waiting list in New York may be full. You can talk with any of the research nurses at the following numbers:

Boston: Beth Israel Hospital, ACTU Clinic, (617) 735-4103
Minneapolis: University of Minnesota, ACTU Clinic, (612) 625-1462
New York: New York University Medical Center, ACTU Clinic, (212) 263-6565 ▼

Combination Drugs to Decrease Toxicity of AZT

{reprinted from Treatment Issues, Vol 5, #7}

A report from a group of investigators in Los Angeles claims success in preventing low red blood cell counts (anemia) and low white blood cell counts (neutropenia) related to AZT by using the combination of erythropoeiten (EPO) and granulocyte-colony stimulating factor (G-CSF). Twenty-two anemic and neutropenic patients with AIDS or ARC interrupted their AZT therapy and received recombinant EPO (product name, EPOGEN) and G-CSF. Patients had increases in both red and white blood counts within two to eight weeks.

Once AZT was restarted, six patients developed anemia, requiring blood transfusions and another interruption of AZT therapy; however, the remainder were able to tolerate large doses of the drug without recurrence of anemia or neutropenia. Opportunistic infections occurred in 14 patients, yet were treated successfully (many with ganciclovir) without recurrence of neutropenia. This small study, reported in a recent issue of *Blood*, suggests that the combination seems safe and is effective in counterbalancing the main hematologic side effects of AZT. Unfortunately, both of these drugs are administered by injections and both are very costly. ▼

ddI Resistance

{reprinted from Treatment Issues, Vol 5, #7}

Dr. Michael Bach of Maine Medical Center, reported in Florence that 6 patients who had AZT-resistant strains of HIV were treated with ddI for 12-15 months. Four patients had dramatic responses to ddI with drops in p24 antigen levels. The virus, however, became increasingly resistant to ddI, and 4 patients eventually deteriorated and died. But after 12-15 months off AZT, virus obtained from these patients had recovered sensitivity to AZT. This implies that AZT may still be beneficial to patients who develop resistance, since the virus may eventually be able to regain sensitivity to the drug. ▼

Surviving The Holidays {Cont'd from pg 1}

(3) Do something to remember the loved one. "Remembering" is critical to grief processing. For the griever: Do something special to honor the memory of your loved one--

- ~ give a donation in their memory
- ~ buy yourself a gift "from" them
- ~ write them a letter telling them how much you miss them and put it under the tree

For those close to someone in grief:

- ~ Don't ignore their loss
- ~ Don't pretend that "everything is the same"
- ~ Do something to remember their loved one:
  - ~ Send a plant (I suggest plants rather than flowers because it is a remembrance that goes on living)
  - ~ Share your concern for the one in grief but try not to overwhelm them with your grief
  - ~ Give a donation in honor of the deceased - a gift to help others
  - ~ Prepare a special meal or box of goodies for them
  - ~ Include them in holiday festivities but respect their need to decline the invitation
  - ~ Let them know that a whole range of feelings are normal grief reactions: happiness, sadness, anger, loneliness, resentment and confusion.

Remember that grief takes time and work and each person's time-table is uniquely their own. Each person will react to grief loss differently.

The greatest gifts you can give yourself and others during this time are love, patience and understanding. Be flexible. Be caring. Be loving. ▼

Less Costly/Better PCP Prevention

{reprinted from Treatment Issues, Oct 1991}

Trimethoprim/sulfamethoxazole (brand names, Bactrim or Septra) is a drug for preventing Pneumocystis carinii pneumonia (PCP) which has recently been deemed superior to the standard (and significantly more expensive) treatment, aerosolized pentamidine (AP). This news comes from the results of a federally-funded study (ACTG #021), in which the risk of recurrent PCP was found to be 3.25 times greater in patients taking AZT with AP than in patients taking AZT with Bactrim or Septra. Some people experience severe allergies to Bactrim or Septra, as they are similar sulfa drugs both made of trimethoprim/sulfamethoxazole (TMP/SMX). For those without sulfa allergies, the savings from taking Bactrim or Septra may reach $3,000 per patient per year. ▼

AIDS and Your Religious Community

A Hands-On Guide for Local Programs features profiles of 27 working models - from monthly suppers to pastoral care - plus tips on community needs assessment, program planning and volunteer management.

Designed for anyone considering AIDS ministry, this guide offers detailed information on social action issues and ongoing battles for research and funding. Also included is a

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AIDS and Your Religious...{Cont'd from pg 3}

valuable resource section listing books, audio-visual materials and helpful organizations.

Priced at only $12.95, *AIDS and Your Religious Community* is an excellent investment. Save 10% if you buy 5 to 9 copies, save 20% on 10 or more. There is a one-time $2.50 handling charge.

About the authors:

* Warren J. Blumenfeld, writer, is co-author of *Looking at Gay and Lesbian Life* and editor of *Homophobia* - both published by Beacon Press. Co-producer of the film *Pink Triangles*, he is also an anti-oppression facilitator and actively involved in the AIDS self-empowerment movement.

* The Rev. Scott W. Alexander, project director, is Senior Minister of the Church of the Larger Fellowship, Unitarian Universalist. Editor of *The Welcoming Congregation: Resources for Affirming Gay, Lesbian and Bisexual Persons*, he has also served the Unitarian Universalist Association as Director of the AIDS Action and Information Program.

To order, write to: UUA Bookstore, 25 Beacon Street, Boston, MA 02108; (617) 742-2100. ▼

Flu Shots Recommended

{reprinted from AIDS Treatment News, #138, November 1, 1991}

The flu season may be more severe than usual this year (although no one knows for sure), and the U.S. Department of Health and Human Services has recommended that "everyone at particular risk...should get vaccinated soon." We called the office of Marcus Conant, M.D., who has a large AIDS practice in San Francisco, and learned that physicians are recommending flu shots for patients with AIDS or HIV, except for those allergic to eggs, or who are pregnant, or who have some special medical reason for not receiving the shot. Most physicians in San Francisco at least are providing the shots to their patients for a nominal charge to cover the cost of the syringe, since physicians get the vaccine free from the Health Department.

Note that the U.S. Centers for Disease Control also recommends that persons with HIV have an annual TB screening, and a one-time Pneumovax (pneumococcal vaccine) injection. ▼

NAC: Important Study Needs Volunteers

By John S. James

{reprinted from AIDS Treatment News, #138, November 1, 1991}

A small but important 15-week study of the experimental HIV treatment N-acetylcysteine (NAC) has been delayed because of lack of volunteers. The reasons few people have volunteered have been (1) this trial was not widely known, although it was listed in some directories; (2) until recently it was only open to residents of the Washington, DC area (since no travel funds were available); and (3) there is some discomfort involved, as the drug is given intravenously for part of the time, and one lumbar puncture is required. On the other hand, NAC is much safer than most experimental drugs, and the trial will give participants the best blood work available anywhere, including repeated plasma viremia tests, at no cost. No hospitalization is required. The entry criteria are easy to meet. Since travel expenses cannot be paid, persons from anywhere in the U.S. can volunteer. And it is important for the AIDS community that this study be completed.

The trial is being run by the U.S. National Institute of Allergy and Infectioius Diseases (NIAID) at the National Institutes of Health campus near Washington, DC; it is sponsored in part by Zambon Corporation of East Rutherford, New Jersey, a subsidiary of the Italian pharmaceutical company which is developing NAC as a potential HIV treatment. A total of 16 volunteers are needed; seven are already in the trial, and three others are waiting to start.

NAC has long been used in Europe as a bronchitis treatment. In the U.S., it is approved for aerosol use in treating bronchial mucous associated with cystic fibrosis and other lung conditions, and also as an antidote for poisoning due to acetaminophen (e.g. Tylenol) overdose. Laboratory studies by several different research groups have built a strong case that the drug should be tested as a treatment for AIDS or HIV; we hope to review these studies in a future issue of *AIDS Treatment News.*

NAC is widely available in buyers' clubs and health food stores, and is already in wide use as one of the most common "alternative" treatments. But until trials are done we cannot know for sure that it is working, or (if it is) how to use it best. There are anecdotal reports of cases of significant benefit, but there are also people NAC seems not to help. And the theory and laboratory data suggests that in many cases benefit might be long-term, with no way to tell quickly if the treatment is working - especially for those who are healthy to begin with and have no obvious illness to indicate possible benefit from the drug.

The NIAID trial will not by itself tell if NAC is useful, but it will provide data to improve the design of larger studies, which will soon be ready to begin. This early trial will determine how well the drug is absorbed, and how well it crosses the blood-brain barrier, in persons with AIDS or HIV. It will also test if there is any drug interaction between NAC and AZT, ddC, or ddI. And it will obtain preliminary data on whether NAC reduces viremia, or improves T-helper counts or other measures of immune functioning. Although no surprises are expected, it is good practice to do a small, rapid test like this to help assure that later studies are optimally designed.

Volunteers must be HIV positive and have T-helper counts less than 500 (there is no lower limit). They can be using AZT, ddI, or ddC (through the expanded-access program), but must not use experimental drugs except ddC during the study; those with T-helper count under 200 should also be on pneumocystis prophylaxis, either by aerosol pentamidine or by oral drugs. They cannot have a serious infection when they begin the study; those with KS are eligible, but must not have received systemic therapy for KS (other than alpha interferon) within two months of starting the NAC study. There are also various medical exclusion conditions, including certain abnormal blood counts and blood-chemistry tests.

Potential volunteers should call Ms. Chris Boenning, RN, MSN, (800) 772-5464 ext 401. ▼

{For information on how to subscribe to AIDS Treatment News, write to: AIDS Treatment News, P O Box 411256, San Francisco, CA 94141; or call (800) TREAT-1-2}